

foster and encourage the beneficent instincts of those who work within them is a far more difficult task than changing attitudes or even beliefs. Changing organizational behavior is a harder, more time-consuming, and slower process and requires more scarcely available skills than changing individual attitudes, even among groups of individuals.

To ensure that dying patients are per-

mitted as much informed self-determination and treated with as much dignity as possible, it is not enough to educate or reeducate entire generations of physicians, nurses, and administrators. We must also figure out how to make hospitals, as complex organizations fulfilling multiple tasks and operating under multiple constraints, operate in a way more consonant with such values. That's a

more daunting task, but one no less compelling. □

References

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ABSTRACT

Objectives. How do health care professionals assess the care of hospital patients near the end of life? Are physicians and nurses aware of and in agreement with national recommendations regarding patients' rights to forgo life-sustaining medical treatments and to receive adequate pain control?

Methods. We surveyed 687 physicians and 759 nurses in 5 hospitals.

Results. Almost half (47%) of all respondents and fully 70% of the house officers reported that they had acted against their conscience in providing care to the terminally ill. Four times as many respondents were concerned about the provision of overly burdensome treatment than about undertreatment.

Conclusions. In summary, many physicians and nurses were disturbed by the degree to which technological solutions influence care during the final days of a terminal illness and by the undertreatment of pain. However, changes in the care of dying patients may not have kept pace with national recommendations, in part because many physicians and nurses disagreed with and may have been unaware of some key guidelines, such as the permissibility of withdrawing treatments. (*Am J Public Health*. 1993;83:14-23)

Decisions Near the End of Life: Professional Views on Life-Sustaining Treatments

Mildred Z. Solomon, EdD, Lydia O'Donnell, EdD, Bruce Jennings, MA, Vivian Guilfooy, MA, Susan M. Wolf, JD, Kathleen Nolan, MD, Rebecca Jackson, BA, Dieter Koch-Weser, MD, PhD, and Strachan Donnelley, PhD

Introduction

Public interest in decisions regarding the use of medical technologies and pain control near the end of life is strong and growing. Many Americans fear that in the terminal stages of an illness, they will receive more medical care and less pain relief than they want. Popular commentators often speak of a "technological imperative," whereby medical interventions are employed simply because they are available. This concept sometimes carries with it the implication that health care professionals, and physicians in particular, are responsible for the imposition of unwanted care on patients.¹⁻⁵

In recent years, a growing number of authorities have proposed ethical guidelines for addressing a host of difficult questions about the use of life-sustaining medical technologies. Recommendations have appeared in the report of a special presidential commission⁶; in a major congressional report⁷; in state-level recommendations⁸; in the policy statements of national organizations such as the American Medical Association⁹ and the American Nurses' Association,¹⁰ among others¹¹⁻¹⁵; in guidelines from a nationally known bioethics research institute¹⁶; and in professional journals.¹⁷⁻²⁵

The vast majority of these documents outline essentially similar ethical criteria and guidelines for upholding patients' rights to make decisions regarding their treatment.

They recognize the right of competent patients to forgo treatment, even if refusal may lead to death; they support deference to patients' wishes to withhold or withdraw life support of all kinds, from cardiopulmonary resuscitation and mechanical ventilation to antibiotics; they encourage the use of advance directives to guide treatment once the patient has lost the ability to make decisions; and they call for the provision of adequate pain relief and palliative care. A central tenet is the right of patients to refuse medical treatment they find unduly burdensome.

Moreover, these guidelines are in accord with legal principles. Beginning with the *Quinlan* decision in 1976,²⁶ a large number of court cases have upheld the rights of competent patients to refuse unwanted life-sustaining treatment and the authority of family members or other appropriate surrogates to refuse on behalf of incompetent patients.²⁷ Nearly all states

Mildred Z. Solomon, Lydia O'Donnell, Vivian Guilfooy, Rebecca Jackson, and Dieter Koch-Weser are with Education Development Center Inc, Newton, Mass. Bruce Jennings, Susan M. Wolf, Kathleen Nolan, and Strachan Donnelley are with The Hastings Center, Briarcliff Manor, NY.

Requests for reprints should be sent to Mildred Z. Solomon, EdD, Decisions Near the End of Life Program, Education Development Center Inc, 55 Chapel St, Newton, MA 02160.

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have recognized the force of advance directives—treatment directives, proxy appointment documents, or both—through legislation, court decisions, or both. In 1990, the Supreme Court noted in the *Cruzan* decision that Constitutional protection for the right to refuse treatment could be inferred from the Court's earlier decisions.²⁸ In 1990, the US Congress passed the federal Patient Self-Determination Act, which ties Medicaid and Medicare reimbursement for hospitals and other health care facilities to the requirement that patients be informed about their right to accept or refuse medical or surgical treatment and the right to formulate advance directives.²⁹⁻³¹

The consensus manifested in these rulings and laws is also reflected in hospital accreditation standards. The Joint Commission's 1992 Accreditation Manual for Hospitals requires institutions to have mechanisms for supporting patients' rights and participation in health care decision making and requires that institutions have a system for educating staff about the appropriate use of advance directives.³²

In short, there is now a body of literature, policy, law, and regulation that presents a generally agreed upon set of basic principles, as well as procedural recommendations for incorporating those principles into clinical practice. However, there has been very little research to determine whether clinicians know about these recommendations, agree with them, or find them useful. Nor do we know how health care professionals themselves see the issues.

To explore these questions, we conducted a survey at five hospitals. Our research questions were as follows: (1) How do health care professionals, observing practices at their own hospitals, assess the care of patients near the end of life? Are clinicians themselves concerned about the misuse of available technologies? (2) Are physicians and nurses aware of the national recommendations regarding patients' rights to forgo treatments of various kinds and to receive adequate pain control? If so, are they in agreement with those recommendations?

The results of our survey reveal an important gap between the views of practicing clinicians and the prevailing guidelines. The data also reveal important differences in the views of attending physicians, house officers, and nurses. In this paper we analyze these differences. We suggest strategies for bridging the gap

between guidelines and clinicians' views and for improving the care of patients near the end of life.

Methods

Sample

The survey was conducted as part of the field test of Decisions Near the End of Life, an institution-based, multidisciplinary continuing education program that addresses ethical issues inherent in decisions about the use of life-sustaining treatments for critically and terminally ill adults.³³ The survey (called the Institutional Profile) was used to collect baseline data on the knowledge, attitudes, and self-reported practices of professional staff in order to target and individualize educational programs that were later administered at each site. The five field test hospitals are located in Massachusetts; Georgia; Washington, DC; and California; they include a city hospital, a Catholic community hospital, and three urban teaching facilities, and range in size from 180 to 660 beds. At all five institutions, there was administrative support for committing staff time to an on-site ethics education program, surveying staff on topics not often addressed explicitly, and discussing results in multidisciplinary grand rounds and seminars.

The total sampling pool consisted of medical and surgical attending physicians, house officers on the medical and surgical services, nurses, social workers, clergy, and others (e.g., administrators involved in decision making and respiratory therapists) who work with critically and terminally ill adults at each of the institutions. Each participant received the seven-page Institutional Profile and a cover letter that urged its completion and that was signed by key leaders at each institution. Those who did not respond received one follow-up questionnaire.

In this paper, we report on the physician and nurse data only. Questionnaires were completed by 687 physicians and 759 nurses; the response rate was 61%, similar to those of other surveys requiring physician completion.³⁴⁻³⁷ Among the 687 physicians, 369 (54%) were on medical services, 174 (25%) were on surgical services, and 144 (21%) were house officers. Respondents had an average of 14.3 years of experience in their profession. Surgical and medical attending physicians had the most years of experience at their institutions (13.6 and 12.7 years, respectively), followed by nurses (8.0 years) and house officers (2.9 years). Re-

spondents described 26% of the patients they had had in the last year as critically or terminally ill; an average of approximately 11 patients in each respondent's care had died over the previous 12 months. Surgeons reported having the fewest critically and terminally ill patients; nurses reported having the most.

Instrument Construction

The Institutional Profile, which contains 123 items, is a self-completed questionnaire covering a range of issues, including the following:

- Knowledge and attitudes regarding the law, medical ethics, and ethical guidelines for clinical practices.
- Knowledge of and adherence to institutional guidelines on the use of life supports.
- Practices surrounding the use of life supports and patient involvement in decision making.
- Perceived impediments to good decision making and quality care.

The items were developed in consultation with national experts in ethics, medicine, nursing, and health law, and through a review of the literature on ethical guidelines for treatments near the end of life.³⁸ During pilot testing with 72 subjects, face validity, test mechanics, and test-retest repeatability were assessed. Test-retest repeatability over 1 month on individual items (measured on five-point Likert scales) ranged from 84% to 94%.

Analysis

Frequencies and mean scores were computed for individual items. Questions with ordinal response categories were cross-tabulated by profession, gender, and prior ethics education, as measured by the question, "Have you ever taken any courses in medical ethics?" Differences in responses by profession were assessed through Kruskal-Wallis nonparametric one-way analysis of variance. Items are not reported by gender and prior ethics education because the effect of gender could not be differentiated from profession (in that almost all nurses were female) and because, as measured here, ethics education had no appreciable influence on any of the items. All statistical analyses were performed with the personal computer version of the *Statistical Package for the Social Sciences*.

TABLE 1—Percentages of Health Care Professionals Reporting Satisfaction with Patient Involvement in Treatment Decisions

	Overall	Medical Attending Physicians	Surgical Attending Physicians	House Officers	Nurses	χ^2_{2a}
On a scale where 1 = not very satisfied and 5 = very satisfied, how satisfied are you with the extent to which						
Patients are informed of different care alternatives	36 (3.04)	49 (3.40)	50 (3.51)	43 (3.23)	25 (2.75)	119.0
Patients understand the information they are told about their condition and treatment alternatives	33 (3.05)	42 (3.31)	49 (3.46)	38 (3.22)	26 (2.80)	86.5
Patients get the help they need to make decisions about care alternatives	33 (3.00)	43 (3.29)	44 (3.38)	35 (3.08)	26 (2.77)	77.4
Staff find out what critically and terminally ill patients want	31 (2.97)	40 (3.22)	39 (3.32)	27 (2.91)	26 (2.79)	51.4
Patients' wishes are recorded in the medical record	29 (2.88)	37 (3.17)	36 (3.19)	37 (3.14)	21 (2.64)	75.7
Ethical issues in a patient's care are discussed by staff	31 (2.88)	39 (3.16)	31 (3.07)	31 (2.99)	26 (2.69)	43.8

Note. Percentages represent respondents who answered with scores of 4 or 5. Numbers in parentheses are group mean scores.
^aChi-square from analysis of differences in average rank order of categorical response by profession (Kruskal-Wallis one-way analysis of variance). Differences by profession are significant at $P < .0001$.

TABLE 2—Percentages of Health Care Professionals Reporting Concerns of Conscience

	Overall	Medical Attending Physicians	Surgical Attending Physicians	House Officers	Nurses	χ^2_{2a}
On a scale where 1 = strongly disagree and 5 = strongly agree, to what degree do you agree or disagree with the following statements:						
At times, I have acted against my conscience in providing care to the terminally ill	47 (3.13)	38 (2.79)	34 (2.63)	70 (3.80)	50 (3.27)	83.3*
Sometimes I feel the treatments I offer my patients are overly burdensome	55 (3.39)	58 (3.43)	45 (3.02)	78 (4.01)	51 (3.34)	55.0*
Sometimes I feel we give up on patients too soon	12 (2.10)	15 (2.22)	7 (1.84)	8 (2.05)	12 (2.10)	15.0**

Note. Percentages represent respondents who answered with scores of 4 or 5. Numbers in parentheses are group mean scores.
^aChi-square from analysis of differences in average rank order of categorical response by profession (Kruskal-Wallis one-way analysis of variance).
* $P < .0001$; ** $P = .0018$.

Results

Dissatisfaction with Patient Involvement in Treatment Decisions

Most respondents reported that they were aware of guidelines at their institution about obtaining informed consent (88%); issuing do-not-resuscitate orders (90%); documenting the reasons for such orders (70%); recording patients' wishes in the medical record (69%); and determining patients' capacity to make decisions (65%). Nevertheless, the respondents reported substantial *dissatisfaction* with the way patients at their institutions were actually involved in treatment decisions (Table 1). Only about a third of the overall sample reported being somewhat to very satisfied with patient participation

in various aspects of decision making: 31% were satisfied that staff find out what critically and terminally ill patients want; 33% believed that patients understand the information they are told; and 33% reported that patients get the help they need to make decisions about care alternatives.

Attending physicians appeared the most satisfied with patient involvement, but even their levels of satisfaction ranged from only 31% to 50%. Nurses expressed even greater dissatisfaction; about one in four was satisfied overall, with only 21% satisfied that patients' wishes are recorded in the medical record. Notably, levels of concern among house officers were closer to those of nurses than to those of attending physicians.

Concerns of Conscience

The extent of dissatisfaction with patient involvement in decision making is underscored by providers' concerns about the appropriateness of care provided. As indicated in Table 2, almost half of the providers reported that they had acted against their conscience in providing care to the terminally ill. Professional differences were important: about 7 in 10 house officers, 5 in 10 nurses, and between 3 and 4 of 10 attending physicians reported acting against their conscience.

Comparison of the second and third items in Table 2 reveals that more than four times as many staff were troubled about the provision of overly burdensome treatment than about undertreatment. Fif-

TABLE 3—Percentages of Health Care Professionals Reporting Concerns about the Inappropriate Use of Specific Treatments

	Overall	Medical Attending Physicians	Surgical Attending Physicians	House Officers	Nurses	χ^2 (P)
For the critically and terminally ill patients you care for, how often are you concerned that the following treatments are used inappropriately:						
Mechanical ventilation	67 (2.91)	60 (2.66)	54 (2.44)	78 (3.06)	66 (3.11)	75.4 (P < .0001)
Cardiopulmonary resuscitation	64 (2.80)	61 (2.64)	58 (2.43)	83 (3.43)	69 (2.84)	85.2 (P < .0001)
Artificial nutrition and hydration	54 (2.56)	55 (2.60)	54 (2.43)	52 (2.45)	54 (2.59)	24.4 (NS)
Dialysis	51 (2.71)	42 (2.39)	44 (2.31)	53 (2.78)	50 (2.95)	61.4 (P < .0001)
Antibiotics	42 (2.29)	45 (2.31)	41 (2.24)	35 (2.06)	46 (2.33)	35.7 (P = .0002)
Pain medication	35 (2.10)	37 (2.19)	24 (1.86)	22 (1.78)	38 (2.18)	40.8 (P = .0001)

Note. Percentages represent respondents who answered with scores of 3–5, where 1 = almost never, 3 = sometimes, and 5 = almost always. Numbers in parentheses are group mean scores.

^aChi-square from analysis of differences in average rank order of categorical response by profession (Kruskal-Wallis one-way analysis of variance).

ty-five percent overall, including 78% of the house officers and 58% of the medical attending physicians, reported that they sometimes offered treatments that were “overly burdensome” to their patients. In contrast, only a few, between 7% and 15%, felt that “we give up on patients too soon.” Furthermore, those who reported acting against their conscience were more likely to report concerns about overly burdensome treatment (Kendall’s Tau = .3864, $P < .0001$).

Concerns about the Inappropriate Use of Specific Treatments

Table 3 presents respondents’ perceptions of how often specific treatment modalities were used inappropriately for their critically and terminally ill patients. Respondents expressed concern most often regarding the inappropriate use of mechanical ventilation and cardiopulmonary resuscitation, followed by dialysis and then artificial nutrition and hydration. There were substantial professional differences in the extent of concern about different treatments.

Clinicians’ Views on Issues Addressed in National Recommendations

Table 4 presents the views of health care professionals, by discipline, regarding key issues addressed in numerous guidelines and court cases.

Right to refuse treatment. Eighty-seven percent of the total sample were in agreement that “all competent patients, even if they are not considered terminally ill, have the right to refuse life support, even if that refusal may lead to death.” Similarly, most respondents (87%) agreed

with the statement that “to allow patients to die by forgoing or stopping treatment is ethically different from assisting in their suicide.” Thus, on both of these items there was congruence between caregivers’ beliefs and national recommendations supporting patients’ rights to forgo treatment.^{6–28} However, disparities emerged when we looked at other items.

Common moral distinctions. We discovered, for example, widespread reliance on the distinctions between withholding and withdrawing life support measures and between “extraordinary” and “ordinary” treatments, despite recommendations that these distinctions should not be considered ethically or legally relevant in clinical decision making.^{6–11,16,27,39}

As shown in Table 4, in regard to withholding vs withdrawing treatment, only 34% agreed that “there is no ethical [emphasis in the original] difference between forgoing (not starting) a life support measure and stopping it once it has been started.” This percentage represents 27% of nurses, 38% of surgeons, 44% of house officers, and 43% of medical attending physicians. To assess whether respondents were familiar with national recommendations on this issue and disagreed with them or were simply unaware of current ethical guidelines, we asked whether they agreed or disagreed that “there is an emerging consensus among ethicists that withdrawing a treatment is ethically different from withholding or not starting it.” Although this statement is false, 47% percent of surgeons, 49% of nurses, 42% of house officers, and 35% of medical attending physicians indicated, incorrectly, that it was true. Comparison of responses to these two questions reveals that those

who feel that there is an ethical difference between withholding and withdrawing treatments are more likely to believe that the emerging ethical consensus makes this distinction (Kendall’s Tau = -0.342 , $P < .0001$).

As for “extraordinary” vs “ordinary” treatments, both the President’s Commission⁶ and The Hastings Center Guidelines¹⁶ have argued that decisions about the use of any treatment should hinge not on whether it is labeled “ordinary,” “extraordinary,” or “heroic,” nor on whether it is technologically simple (e.g., antibiotic therapy), but on its potential benefits and burdens to the patient as perceived by the patient or surrogate. Again, the majority of providers surveyed disagreed with this position. With few professional differences, 74% reported that “the distinction between extraordinary (or ‘heroic’) measures and ordinary treatments is helpful in making termination of treatment decisions.”

Artificial nutrition and hydration. Most national guidelines and court cases agree that decisions about forgoing enteral and parenteral nutrition and hydration should be governed by the same ethical and legal principles that guide decisions about forgoing other kinds of life-sustaining interventions.^{25,28,39} Our respondents, however, were divided in their opinions about the appropriateness of forgoing artificial nutrition and hydration. Although across professions only a minority (12%) believed that “disconnecting a feeding tube is killing a patient,” a sizable proportion (42%) agreed that “even if life supports such as mechanical ventilation and dialysis are stopped, food and water should always be continued.” Nurses

TABLE 4—Clinicians' Views on Issues Addressed in National Recommendations

	Overall	Medical Attending Physicians	Surgical Attending Physicians	House Officers	Nurses	χ^2_{2a} (P)
Right to refuse treatment						
All competent patients, even if they are not considered terminally ill, have the right to refuse life support even if that refusal may lead to death	87 (4.48)	86 (4.39)	87 (4.44)	87 (4.49)	89 (4.52)	9.9 (NS)
To allow patients to die by forgoing or stopping treatment is ethically different from assisting in their suicide	87 (4.41)	89 (4.47)	86 (4.44)	94 (4.57)	85 (4.33)	9.0 (NS)
Common moral distinctions						
There is no ethical difference between forgoing (not starting) a life support measure and stopping it once it has been started	34 (2.71)	43 (3.00)	38 (2.84)	44 (2.96)	27 (2.49)	36.9 (P < .0001)
There is an emerging consensus among ethicists that withdrawing a treatment is ethically different from withholding or not starting it	45 (3.31)	35 (2.98)	47 (3.42)	42 (3.16)	49 (3.46)	50.0 (P < .0001)
The distinction between extraordinary (or "heroic") measures and ordinary treatments is helpful in making termination-of-treatment decisions	74 (3.96)	74 (3.88)	77 (4.08)	70 (3.69)	74 (4.02)	16.7 (P = .0008)
Artificial nutrition and hydration						
Disconnecting a feeding tube is killing a patient	12 (1.89)	11 (1.84)	12 (1.89)	9 (1.62)	12 (1.97)	3.9 (NS)
Even if life supports such as mechanical ventilation and dialysis are stopped, food and water should always be continued	42 (3.09)	34 (2.75)	45 (3.15)	36 (2.71)	46 (3.31)	47.8 (P < .0001)
The burdens of continuing nutrition and hydration to a terminally ill patient can outweigh the benefits of prolonging life	48 (3.31)	58 (3.52)	54 (3.38)	59 (3.66)	41 (3.12)	34.2 (P < .0001)
Pain control						
Sometimes it is appropriate to give pain medication to relieve suffering, even if it may hasten a patient's death	89 (4.44)	94 (4.55)	92 (4.52)	92 (4.56)	86 (4.35)	13.3 (P = .0040)
It is possible to prevent dying patients from feeling much pain	87 (4.34)	89 (4.37)	84 (4.30)	91 (4.44)	86 (4.31)	3.1 (NS)
Clinicians give inadequate pain medication most often out of fear of hastening a patient's death	41 (3.01)	37 (2.92)	35 (2.72)	40 (2.87)	44 (3.15)	18.9 (P = .0003)
The most common form of narcotic abuse in the care of the dying is undertreatment of pain	81 (4.24)	85 (4.32)	83 (4.30)	84 (4.39)	78 (4.16)	8.1 (NS)
Dying patients should determine the best dosage regimen to control their pain	66 (3.77)	72 (3.85)	74 (3.96)	76 (3.95)	60 (3.66)	16.8 (P = .0008)

Note. Numbers shown represent the percentage of respondents in each category who answered with scores of 4 or 5 on a 5-point scale where 1 = strongly disagree and 5 = strongly agree. Numbers in parentheses indicate group means.

^aKruskal-Wallis nonparametric one-way analysis of variance.

(46%) and surgical attending physicians (45%) were more likely to believe that food and water should always be continued than were house officers (36%) or medical attending physicians (34%).

To determine whether responses would have been different had this item read "medically supplied nutrition and hydration should always be continued" rather than "food and water should always be continued," we asked a small subsample (n = 40) of respondents to explain how they interpreted the question

and to elaborate on their responses. These respondents indicated that, in the context of the survey, they assumed that this statement referred to medically supplied nutrition and hydration, and that they would not have answered differently had the item been phrased that way.

Despite evident reluctance on the part of many respondents to stop nutrition and hydration, nearly half (48%) reported that "the burdens of continuing nutrition and hydration to a terminally ill patient can outweigh the benefits of prolonging

life." Indeed, the majority of physicians and house officers (from 54% to 59%) agreed with this statement; a substantial proportion of nurses (41%) did so as well. Therefore, we calculated how many of those who acknowledged that "the burdens of continuing nutrition and hydration can outweigh the benefits of prolonging life" also agreed that "food and water should always be continued." Interestingly, there was a positive correlation between the belief that the burdens of continuing nutrition and hydration *can*

outweigh the benefits of prolonging life and the assertion that food and water must always be continued (Kendall's Tau = 0.293, $P < .0001$).

Pain Control

Our results demonstrate strong agreement, in principle, with ethical recommendations regarding pain control^{6,16} that hold that "providing large quantities of narcotic analgesics does not constitute wrongful killing when the purpose is not to shorten [patients' lives] but to alleviate their pain and suffering, and the alternatives have been carefully evaluated and this course found to serve the patient's best interest."^{16,p.73} As Table 4 indicates, 89% agreed that "sometimes it is appropriate to give pain medication to relieve suffering, even if it may hasten a patient's death." Overall, between 60% and 76% agreed with another recommendation^{40,41} offered by some pain control experts: "Dying patients should determine the best dosage regimen to control their pain." Although 87% believed that "it is possible to prevent dying patients from feeling much pain," 81% reported that "the most common form of 'narcotic abuse' in the care of the dying is undertreatment of pain." Just over one third of medical and surgical attending physicians, compared with 44% of nurses, believed that "clinicians give inadequate pain medications most often out of fear of hastening a patient's death."

Discussion

Concerns about Inappropriate, Overly Burdensome Care

This research establishes that health care professionals are themselves deeply concerned about the provision of inappropriate, overly burdensome care to patients near the end of life and about inadequate participation by patients in decision making about treatment. Indeed, the level of dissatisfaction expressed by clinicians in this sample is even greater than the level of dissatisfaction experienced by patients, as reported elsewhere.⁴² Almost half the respondents reported having acted against their conscience in providing care. Most concern centered on overtreatment rather than undertreatment. Both their level of dissatisfaction with the degree to which patients are currently involved in decision making and their expressions of conscience suggest clinicians' frustration with a decision-making process that does not meet their own standards for authentic engagement with patients. Far from being

the willing agents of the so-called technological imperative, these health care professionals are profoundly concerned about it.

If physicians and nurses recognize patients' rights to limit care and if they worry about providing overly burdensome treatments, why then do they report that key interventions, such as mechanical ventilation and cardiopulmonary resuscitation, continue to be offered inappropriately? How can we reconcile high levels of dissatisfaction about current practice with health care professionals' own reports of inappropriate care?

One reason for this inconsistency may be inadequate communication between caregivers and patients in advance of crises and inadequate documentation of patient preferences. Inappropriate care is a logical consequence if—as the respondents in this survey indicated—caregivers do not find out in advance what patients want and do not record their wishes in the medical record. Earlier empirical research on decisions regarding cardiopulmonary resuscitation corroborates the importance of early communication and better documentation.⁴³⁻⁴⁹

Another reason for the high levels of dissatisfaction may be that physicians and nurses hold some views that make it difficult for them to act in ways that would be consistent with their own expressed support for patient autonomy. Although clinicians' views are congruent in many ways with those put forth by authorities in ethics and law, on at least three critical issues—withdrawal of treatment, the distinction between "ordinary" and "extraordinary" treatment, and the provision of nutrition and hydration—many clinicians differ with current national recommendations. On a fourth issue, pain control, clinicians agree with national recommendations but report that practice lags behind.

Reluctance to Withdraw Treatment

Most respondents asserted that withdrawing a treatment is ethically different from deciding not to initiate the treatment. Yet all the national recommendations hold that the same reasoning used to withhold treatment can be used to withdraw it: the patient or surrogate's own assessment of the relative benefits and burdens to the patient, not the timing of the decision, should be determinative. Indeed, many argue that it is preferable to attempt potentially beneficial treatments, with a plan for stopping—that is, instituting a "trial of treatment"—than to withhold

treatment in the belief that it cannot later be stopped.^{6,7,11,16,39} Yet so long as health care professionals feel it is ethically appropriate to withhold, but not to stop, burdensome treatments, patients will not have the benefit of trials of treatment. Potentially beneficial treatments will not be tried, and conversely, overtreatment will continue to be of concern.

As noted above, we conducted follow-up interviews with a small subset of survey respondents. These interviews shed light on the reasons why there may be reluctance to withdraw treatment. Most clinicians interviewed were uncertain about what the law, ethics, and their respective professional standards say on this matter. In addition to this uncertainty, the interviewed respondents reported being less likely to withdraw treatments than to withhold them for a variety of other reasons, including psychological discomfort with actively stopping a life-sustaining intervention; discomfort with the public nature of the act, which might occasion a lawsuit from disapproving witnesses even if the decision were legally correct; and fear of sanction by peer review boards. Moreover, some of the physicians expressed discomfort about openly soliciting patients' views on what would constitute an acceptable quality of life. They tended not to acknowledge explicitly to patients (or their families) that many termination-of-treatment decisions involve personal judgments about quality of life as well as clinical considerations about medical efficacy.⁵⁰

Reliance on the Distinction between "Ordinary" and "Extraordinary" Treatments

In the follow-up interviews, we also explored why the vast majority of survey respondents agreed that "the distinction between 'extraordinary' (or 'heroic') measures and 'ordinary' treatments is helpful in making termination-of-treatment decisions." Approximately half of those interviewed used the ordinary-extraordinary distinction to capture a sense of going beyond what was an appropriate level of treatment for a given patient. Although it is not completely clear, the use of this distinction may approximate the benefits and burdens assessment advocated by authorities in ethics. Thus, although on the surface these clinicians would appear to disagree with national recommendations eschewing the ordinary-extraordinary distinction, the decision-making criteria they employ may be consonant with those recommendations.

In contrast, the other half of the interviewees seemed simply to rely on the level of technological complexity to guide their thoughts. One disadvantage of focusing on technological complexity rather than on what the patient perceives (or would have perceived) to be the balance of benefits and burdens is that the patient's preferences do not guide the decision. Another disadvantage is that the ordinary-extraordinary formulation can make it easier to forgo more complex interventions and harder to forgo more technically simple ones, such as antibiotics, transfusions, and medically supplied nutrition and hydration.

No one in our subsample explicitly used the benefits and burdens formulation advanced in the literature. Thus, despite efforts on the part of some ethicists to encourage a shift away from reliance on the ordinary-extraordinary distinction, this language appears to be used—with different meanings—by a very high proportion of clinicians.

Reluctance to Forgo Artificial Nutrition and Hydration

A sizable proportion of our survey respondents believed that medically supplied food and water should always be provided. Our interview data suggest that clinicians who hold this view have a desire not to abandon highly vulnerable persons and a fear of inducing discomfort. Thus, many clinicians may not be aware of research suggesting that some imminently dying patients do not experience hunger and that dehydration may reduce suffering in the final hours of life.^{40,51–54}

In addition, our findings provide empirical support for Meisel's assertion³⁹ that providers are simply unaware of the national recommendations and legal consensus allowing the withholding and withdrawal of medically supplied nutrition and hydration. First, during the follow-up interviews, many physicians and nurses revealed that they were unaware of what law, ethics, and their own professional societies say on this topic.⁵⁰ Second, some of those who asserted that medically supplied food and water must never be withdrawn nonetheless recognized that such support can become overly burdensome. Some of these clinicians may continue to offer a treatment even when it has become overly burdensome because of their reliance on the distinction between extraordinary and ordinary treatments. By defining the provision of nutrition and hydration as ordinary, caregivers may place it in a category of treatment that

must always be provided, despite the patient's preferences or best interests.

Recognition of the Need for Better Pain Relief

These survey results corroborate the view that as a nation we must do a better job of providing pain relief for the dying. Indeed, the vast majority of the clinicians we surveyed asserted that “the most common form of narcotic abuse in the care of the dying is undertreatment of pain.” Many others have called attention to this problem.^{24,55–65} Inappropriate management of pain is due partly to lack of knowledge of appropriate techniques for pain control^{59–61} and partly to misplaced fear of causing addiction.^{60,62–63} Our data suggest that it is also related to fear of providing a last, lethal dose. Without additional education about the ethical grounds for using adequate levels of pain medication as well as the pharmacology and medical management of pain control, health care professionals in the United States are likely to remain poorly prepared to treat pain effectively in dying patients.

Recommendations

Disseminating and discussing guidelines. In interpreting the data and attempting to explain the tension between expressions of support for patient autonomy and concerns about overtreatment, it is important to consider the possibility that the physicians and nurses who were most troubled about the care they witnessed were more likely to complete the survey than were others for whom ethical issues are less salient. Similarly, it is possible that institutions willing to undertake this survey and educational program have heightened concern about ethical issues. Indeed, we may be seeing such high levels of dissatisfaction because we have surveyed sites and clinicians with hopes for improvements in end-of-life care. They may be frustrated that current clinical realities do not meet their expectations. If this is the case, this group's lack of knowledge of key guidelines is all the more compelling: one would expect even less knowledge in those who chose not to participate because of lack of interest in ethics.

Thus, it is reasonable to infer that many health care professionals persist with treatments both they and their patients (or their patients' families) recognize as inappropriate because they are unaware of some pertinent national recommendations regarding the use of life-sustaining treatments. We strongly recommend more deliberate attempts to

bring these recommendations (and the reasoning that lies behind them) to the attention of hospital caregivers. Guidelines can be of little use if they are not fully understood and vigorously implemented.

However, as other attempts to change medical practice have demonstrated, the mere publication of guidelines is not enough to ensure their implementation.^{66–69} Therefore, we propose several other recommendations for improving knowledge and practice among health care professionals providing care to the critically and terminally ill.

Attending to the psychology as well as the ethics of moral decision making. If we expect to motivate changes in caregivers' behavior, we must pay attention to the psychology as well as the ethics of moral decision making. For example, for many practitioners, it does feel worse to withdraw than it does never to have initiated a course of treatment. Such feelings are probably a natural consequence of clinicians' strong attachment to patients. In encouraging clinicians to withdraw overly burdensome treatments, we must be careful to emphasize that this is not an abandonment of patients and need not break the strong bonds between caring professionals and trusting patients. Therefore, educational efforts must not only address ethics; they should also allow clinicians to reflect on the inevitable burdens and conflicts they experience as they provide care to patients near the end of life.

Encouraging multidisciplinary discussion of ethical issues. This study also points to the importance of encouraging discussion among nurses, house officers, and attending physicians. Nurses and house officers have markedly lower levels of satisfaction with the degree to which patients are involved in treatment decisions than do attending physicians. In general, across survey items, house officers expressed concerns that were closer to those of the nursing staff than to those of attending physicians, probably reflecting the fact that residents and nurses are often the implementers of decisions in which they have not participated and with which they may not agree. Both nurses and house officers could probably play a greater role in helping patients understand the choices they face. Yet, as other researchers have noted, nurses are often uncertain about taking this more active role, particularly when physicians do not invite them to engage in discussion with patients about their treatment preferences.^{70–72} Our findings suggest that house officers are also in need of more guidance from

attending physicians about the roles they are expected to play in the decision-making process. For example, the finding that most house officers have acted against their conscience while providing care suggests an urgent need for better communication between attending physicians and physicians in training about patients' wishes and the reasons for treatment or nontreatment. Attending physicians are in a pivotal position: they have the ability to initiate cross-disciplinary communication and could encourage nurses and house officers to offer their perspectives on treatment decisions.

Furthermore, the survey reveals not only differing levels of satisfaction with patient involvement in decision making, but also disagreement among professional groups about some key recommendations. Consider, for example, that nurses are more likely to question the ethics of stopping a treatment that has already been initiated than are physicians. This difference in viewpoint is a source of potential conflict that should be addressed. We believe it is in the best interests of health care institutions and, ultimately, patients and families, to provide a forum in which professionals with different roles and responsibilities can work together toward a common goal of improving the care of dying patients.

Improving dialogue between those who develop ethical recommendations and those who practice at the bedside. It has been suggested that applied ethics has had little relevance to clinicians because "bioethics as a discipline doesn't seem to be in possession of the realities of practice."⁷³ Although it is likely that real-life moral decision making as it is experienced by both physicians and patients is more context dependent, less static, and less amenable to formal deductive logic than theories of normative ethics assume,⁷⁴ these findings suggest that the relevance of applied ethics has not yet been fully tested. Unless and until practitioners are aware of and understand the norms established by the field, we cannot expect to determine the relevance of those norms. We have yet to see the help they might offer.

However, we do not mean to imply that all that is needed is better communication from ethicists to clinicians. On the contrary, clinicians should question and, when appropriate, challenge current recommendations, suggesting more relevant ones. However, that process should be one of mutual accommodation, grounded in knowledge of the relevant debates, and a product of reasoned reflection. Suppose, for example, that physicians and nurses

were fully apprised of current recommendations regarding the permissibility of withdrawing medically supplied food and water and despite that knowledge continued to maintain that the provision of artificial nutrition and hydration should be classified differently than other treatments. Indeed, some authors have stressed the important symbolism of providing nutrition and hydration and have cautioned that extra care should go into the decision to withdraw them.⁷⁵⁻⁷⁸ An exchange of views in which the reasoning behind both current ethical recommendations and caregivers' perspectives is examined ought to yield a deeper understanding of the values at stake and a more deliberate approach to decisions about patient care.

Moving from guidelines to actual changes in policy and practice. Guidelines alone cannot result in changes in policy and practice. Other research indicates that even when recommendations exist they may not receive proper attention⁷⁹⁻⁸⁰ and that patients are not getting the information about their conditions and treatment options that would enable them to make informed decisions.⁸¹⁻⁸³ Therefore, institutions must find concrete ways to improve critical and terminal care that go beyond the provision of staff education.

Hospitals implementing the Decisions Near the End of Life program have used data derived from this survey to effect significant improvements. Two hospitals, for example, have improved their do-not-resuscitate policies; another facility has revised its policy on the use of artificial nutrition and hydration so that patients who wish to forgo feeding tubes may do so without resorting to court intervention. A fourth institution has developed more extensive education regarding pain control. If national recommendations are to make a real difference, still other areas need attention. Physicians and nurses might, for example, assess how well their institutions are communicating with patients about advance directives, or they might develop mechanisms for providing surrogate decision makers for the incapacitated patients they serve who have no one to speak on their behalf. These are the sorts of actions that are likely both to serve patients' interests and to improve clinicians' satisfaction. Moreover, if improvements of this sort are to become prevalent and enduring, we need to look beyond the walls of individual hospitals. In addition, we need to identify external barriers and incentives that affect decision making, such as reimbursement

patterns, federal regulations, and conventional peer review standards.

Our society has struggled for well over a decade to define appropriate ways to use the life-sustaining medical technology available to us. Intensive ethical and legal analysis has resulted in a useful framework for handling these problems in a more rational and informed way. There is no doubt that health care professionals and the hospitals where they work can, with the guidance of existing recommendations, help dying patients remain in control of their medical and personal destinies. However, there is still far to go. Our results suggest that physicians' and nurses' own discontent with the status quo should be used to inform future recommendations and to motivate improvements in clinical practice. □

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Commentary: Balancing Life and Death—Proceed with Caution

Nancy Neveloff Dubler, LLB

ABSTRACT

Hospital professionals' decisions to permit death are amalgams of medical, ethical, and legal judgments. Medical education and socialization and the business of health all focus on offering and providing treatment, not on facilitating death. Some patients are suspicious that rights to refuse care will foster abandonment by care providers. Lawyers and risk managers often let exaggerated fears of future liability limit patients' and families' rights. The culture of medical institutions must change to accommodate notions of negotiated death. (*Am J Public Health.* 1993;83:23-25)

In this Public Health Policy Forum, Solomon et al.¹ present compelling data that indicate that a patient's last days may not be as comfortable and pain-free as good medicine and humane care should demand. My observations certainly support such an assertion. Nonetheless, I suspect that the authors' conclusion—that national recommendations are insufficiently respected as guidelines for care—fails to take into account the huge chasm that separates abstract principles from the messy reality of patient care.

Conceptual language is best suited to the presentation of principles and the analysis of concepts. Case material best illuminates anguish and explains ambivalence. Consider the following case, in which all identifying elements have been changed to shield the identity and protect the privacy of the patient and family:

Mr. B. was an 83-year-old White male who had taught piano for most of his adult life. In his late 70s he had developed diabetes, complications of which had led to one below-the-knee amputation and blindness in one eye and impaired vision in the other. He had also developed severe arthritis that prevented him from playing the piano pieces he had committed to memory over a lifetime. At the time of his hospital admission, he was homebound and confined to a wheelchair with a 24-hour home attendant and visiting nurse services. The patient's grandson had married recently, an event that Mr. B. had awaited eagerly. Shortly

after the wedding he experienced difficulty breathing and was admitted to the hospital, where he was transferred almost immediately to the intensive care unit.

After 4 weeks of intensive care the patient had deteriorated rapidly. He was on a ventilator with a tracheostomy and on vasopressors, livopened, and dialysis. He drifted in and out of consciousness. The physician presented Mr. B.'s prognosis to the family. On the basis of the patient's septic shock, multiple organ failure, and progressive downward course, the physician concluded that there was less than a 1% chance that the patient would recover to leave the intensive care unit, let alone leave the hospital. In response to this statement, Mr. B.'s daughter, who visited him at the beginning and end of every day, stated that she possessed her father's living will, executed in the year before his admission, and that she thought that the time had come to follow its directives.

The nurses caring for Mr. B. stated that they thought that, despite his disabilities, he was capable of making the decision to terminate care. They reported that whenever he was at all lucid he mouthed "enough," "I want to die." These state-

The author is with the Division of Bioethics, Department of Epidemiology and Social Medicine, Montefiore Medical Center/Albert Einstein College of Medicine, Bronx, NY.

Requests for reprints should be sent to Nancy Neveloff Dubler, LLB, Division of Bioethics, Department of Epidemiology and Social Medicine, Montefiore Medical Center/Albert Einstein College of Medicine, 111 E 210th St, Bronx, NY 10467.